THE IMPACT OF CANCER ON THE FAMILIES OF FIFTEEN CANCER PATIENTS AT COOK COUNTY HOSPITAL

A THESIS

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TO MY LOVING FAMILY

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CHAPTER I

INTRODUCTION

The Significance of the Study

Mankind has been afflicted with tumors for many years. There has been evidence that very early civilizations show that there was occasional destruction of bones which seemed to be caused by cancer. Today no race, nationality, or ethnic group seems to be free of cancer.[1]

Cancer is the uncontrolled or irregular growth of cells. It is a malignant tumor which metastasizes. This means that it is an abnormal growth of cells which tend to go from bad to worse and tend to spread and invade many areas of the body. The two general classes of cancer are sarcomas which are cancers of the connective tissues (bones and muscles) and carcinomas which involve the epithelia (covering or lining) tissues.[2]

Several authors suggest that cancer is a large class of individual diseases having similar and dissimilar characteristics. The commonest lies in the fact that it involves abnormal cell growth. These diseases have many differences in symptoms, behavior, and response to treatment.[3] Some types of cancer progress slowly, others rapidly; in some instances cancer can be cured and in others it cannot. Cancer may develop in any part of the body, but some parts are more susceptible to it than others.

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1 Charles Cameron, The Truth About Cancer (Englewood Cliffs, 1956), p. 23.

2 Ibid., pp. 13-22.

3 Ibid., p. 14.

These parts are the mouth, lungs, stomach, rectum, prostate, breast, and uterus.[1] Many authors indicate that the treatability of the cancer depends on the site of the infection.

Research indicates that cancer can be cured if it is treated before its metastasis becomes uncontrollable.[2] Three accepted ways of treating cancer are X-ray and radium therapy, chemotherapy, and surgery.[3] In spite of the advancements in scientific research on cancer there is still a great deal of uncertainty associated with it and it continues to cause a great many deaths.

Many problems are created by this illness. Among these are social economic, familial or emotional problems. There are also varying amounts of anxiety produced by the illness which distort the medical diagnostic picture. In such instances, family members think only of liabilities, fear the worst, and ignore the real potentialities the patient may have for overcoming his illness. Also, family members often try to shield patients from knowledge of serious or fatal prognosis.

Due to the fact that some basic problems involving medical services and the patients are based on intrafamilial relationship patterns, the trend in medical social work practice, as in other social work practices, is to bring the family constellation into treatment. It is felt that a

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1 Leonard Goldman, There is an Answer to Cancer (New York, 1958), p. 141.

2 Dallas Johnson, Facing the Facts About Cancer (New York, 1947), p. 3.

3 American Cancer Society, Who, What, Where, When of Cancer (New York, 1957).

cooperative relationship should be developed among the doctor, social worker, and the family.

Realizing the interrelatedness of the feelings of the family and the patient, the medical social worker must understand the existing relationship patterns in the family and treat the problems they create in order to provide a milieu where the patient can function to his maximum ability. She can help interpret a more accurate picture of the disease to the patient in terms that can be understood. She should use her casework skills to convey the patient's strengths as well as handicaps so as to lessen the negative feelings about the illness so that the patient again becomes a person and a member of the family who had limitations even when he was well.[1]

It is recognized by both the medical and social work professions that the emotional and social concomitants of cancer are profound and extensive. There are usually negative feelings and adverse social and medical aspects associated with a disease like this. It is also understood that for families, illness in general, usually means problems, changes, and consequent adjustments. What are some of these social and emotional problems families will encounter and have to respond to when faced with having one of their members a victim of cancer?

Some concepts which will need to be defined for the purpose of this study are:

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[1] Dora Goldstine, (ed.), Expanding Horizons in Medical Social Work (Chicago, 1955), pp. 123-130.

Impact---The psychological and sociological force which one experiences upon learning about or having to live with something unpleasant. The social and emotional problems families will have to respond to when faced with having one of their members a victim of cancer.

Family---Any one or more of the following: mother, father, husband, wife, siblings, children, and/or grandchildren of the patient who live with or in proximity of the patient.

Cancer Patient---Any person at Cook County Hospital with a diagnosis of cancer.

General Tumor Service---Includes persons having cancer of any part of the body except the Uterus and Breast who are known to the social service department and who are receiving treatment at the Radiation Center at Cook County Hospital.

Known---Cases active with the General Tumor Social Worker during the period the sample was selected.

Social workers have indicated a realization of the implications a disease like cancer has for families. However, the researcher felt that the more they could learn about the social and emotional problems associated with this disease, the more effective they could be in rendering services to patients and their families. The researcher feels that this study may shed light on some of the problems families will encounter when faced with having one of their members a victim of cancer. This understanding may also be helpful in the formulation of ways to handle these problems.

The Purpose of the Study

The purpose of this study was to find out the impact of cancer on the families of fifteen patients known to the General Tumor Service of Cook County Hospital. The researcher sought to find out the problems of families of cancer patients as identified by the family members.

The Method of Procedure

The researcher made a survey of the literature for background material and to broaden her knowledge of facts concerning elements used in this study.

The method employed in this study was interviewing. The researcher interviewed members of the families of fifteen patients known to the General Tumor Service of Cook County Hospital. From the general tumor worker's active caseload of approximately sixty-one cases for January, 1961, the researcher extracted the records of thirty-eight patients who met her definition of having families. Out of this number, the first fifteen families contacted and interviewed comprised the sample.

A schedule was used to guide the researcher and to help categorize the information obtained from the interview. Some sections of the schedule were designed to show possible problems which the family may have encountered. The respondants were asked to respond to whether these did or did not apply in their situations. Other sections were geared toward soliciting a more detailed response in order to understand some of the emotional feelings involved.

The data in this study were compiled, analyzed, and reported as they related to theoretical knowledge concerning social and emotional problems associated with this disease. In concluding and summarizing, it was the researcher's intention to describe in the study, the findings of other authors on this subject as well as her own.

The Scope and Limitations

The data for this study were collected during the months of January and February, 1961. They included families of fifteen cancer patients

known to the General Tumor Service of Cook County Hospital. Because of the small number of cases studied, the material gathered was not enough to yield evidence to confirm probabilities. It can only give clues for further study and shed light on possibilities. Due to the method of selecting cases and due to the fact that the hospital places some kinds of cancers in another service, the study did not include patients with cancers of all areas of the body. There is a possibility that other factors or problems may be associated with cancers affecting these areas.

CHAPTER II

HISTORY OF THE AGENCY

Setting of the Study

Cook County Hospital, one of the largest general hospitals of its kind in the world, covers over eighteen acres in one of the medical centers of Chicago. It has a bed capacity of more than 3,170 in its General Hospital and Mental Health Clinic. The General Hospital Section, in addition to a main building, includes Contagious, Chest, Male Medicine, and Children's Hospital buildings. These and others, such as the Fantus Clinic, Mental Health Clinic, Radiation Center, and Pathology buildings help to comprise the twenty-one buildings of the hospital. The hospital continues to increase in size and in facilities for rendering services to patients. It is highly noted for its research and pioneer work in medicine.

Cook County Hospital provides medical care on an in-patient and out-patient basis for residents of Cook County who are unable to pay for private medical care. Eligibility for treatment is determined by the Cook County Department of Welfare, the Institutional Service Division, which has an office located in the hospital.[1]

Services to Cancer Patients

Two types of services may be rendered to cancer patients at Cook County Hospital. Cancer patients who are eligible for hospital admission may receive medical care on any ward which renders the type of care and

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[1] "Cook County Hospital" (Chicago, Illinois n.d.) (Mimeographed bulletin).

treatment needed for the particular area of the body where the cancer is located. Cancer patients may also receive treatment on an out-patient basis through the Tumor Clinics. Included among these are breast tumor, gynecology tumor, chest tumor, ear, nose and throat tumor, genital-urinary tumor and general tumor clinics. These patients are usually seen in the radiation department.

The Radiation Treatment Center which houses these Clinics and which also houses modern equipment for the treatment of cancer may be considered a special service of the hospital. Because of the nature of the service, persons who otherwise might be ineligible for hospital care may receive treatment there. Hospitalized patients may also receive treatment there.

Development of Social Service

Social Service was first introduced to patients at Cook County Hospital in 1910 when a worker from the United Charities of Chicago was sent to the hospital to render service to clients who were active with the agency. During the following year, Miss Marion Prentiss, a nurse on the Obstetrical Service, pointed out the serious social situation of the unmarried mothers. As a result, the Cook County School of Nursing explored the situation and discovered the great need for social service in this area. Miss Prentiss was appointed the first social worker in November, 1911, after having been trained at the Chicago School of Civics and Philanthropy.

In 1918, demands for social work in the other services of the hospital brought an increase in the Social Service Staff. However, in 1932, during a financial crisis in the county, the Nursing School voted to discontinue the Social Service Department. Attending Physicians and other interested

persons in the community protested this action and the service was re-instated.

Miss Helen Beckley, executive secretary of the American Association of Medical Social Workers, became the second director in 1934. Upon her resignation in 1939, Miss Josephine G. Taylor, the present director of Social Service became the director.[1]

The Medical Social Service Department of Cook County Hospital, which is supported by and is under the direction of the Cook County School of Nursing, has grown steadily throughout the years. Its function is to help patients and their families solve some of the social and emotional problems which interfere with their recovery and adjustment to their illness or disability.[2]

The General Tumor Worker

Miss Josephine G. Taylor, director of Social Service, recognizing the need and using her administrative skills to interpret this need secured the financial help, on a temporary basis, of the American Cancer Society for securing a General Tumor Worker. This worker was to handle all cancer cases not covered by the breast and gynecology tumor workers. The position was filled in January of 1954.

Miss Taylor worked assiduously toward convincing the Nursing School Board of Directors and the County Commissioners of the need to have this

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1 Josephine Taylor, "General Historical Statements", (Chicago, Illinois, Cook County Hospital, 1955).

2 Annual Message of Daniel Ryan, President of Board of Commissioners of Cook County, Illinois for Fiscal Year, 1959.

service made a permanent part of the hospital's functioning. Her painstaking efforts were finally rewarded when on January 3rd of 1961, this service became a part of the budget of the School of Nursing. Thus, it became a permanent part of the hospital social service department.

The services provided by this worker, as stated by a former general tumor worker, Mr. Cayetano Santiago, Jr. in his 1959 report to the American Cancer Society, are (1) psycho-social evaluation of patient and family, (2) assistance in helping patient and family adjust to the illness, (3) follow-up visits in the hospital wards, (4) assistance with patients and family in making use of community resources, and (5) services to other community agencies with regard to planning for the patient and family.[1]

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[1] Cayetano Santiago, Jr., "Report to American Cancer Society" (Unpublished Report, Social Service Department, Cook County Hospital, Chicago, 1959).

CHAPTER III

SOCIAL PROBLEMS OF FAMILIES STUDIED

Identifying Data

The study group was comprised of families of fifteen cancer patients. An interview was requested by telephone of a member or members of the fifteen families who fell into the category specified by the researcher's definition of the term. The persons contacted were eight wives, three sons, one husband, one granddaughter, one sister, one brother, and three daughters of the fifteen patients. The researcher interviewed eight families at the Social Service Department of Cook County Hospital and seven families in their homes. In selecting the place for the interview, the convenience of the interviewees was considered. The fact that the patients' presence during the interview would influence the families' response was also an influential factor in this selection.

Ten Protestant, four Catholic, and one Jewish family were represented. There were eleven Negro families and four Caucasian families. The ages of the adult members of the families ranged from twenty-nine years to seventy-eight years. Nineteen children whose ages range from eleven months to eighteen years were members of four of the fifteen families.

The researcher found that the responses to certain items of the schedule regarding social problems were very sparse. Perhaps, this limitation to the study was due to the fact that this was a small sample, that the study did not include all areas of the body, that Cook County Hospital and other social service agencies help to alleviate some of the cost of the illness, and/or that these problems did not apply to this sample group. The data from the least represented items were combined

with related items.

Changes in the Financial and Economic Situation

> "The financial and economic costs of illness create natural anxiety in people; many families whenever their financial situations permit attempt to provide in their family budgeting for anticipated medical costs through savings, membership in prepaid health plans, insurance, and so on. However, chronic illness of long duration, extended hospitalization, or illness of breadwinner may create debts or budgetary deficits for which many families are unable to make adequate provisions."[1]

Out of the fifteen families studied, only five families did not experience a financial shift as a result of the illness. Three of these were receiving public assistance before the onset of the illness and the financial cost of the illness was handled by the public assistance agencies. In another family, the husband remained the source of support and the insurance benefits were sufficient to take care of the medical expenses. In the remaining case, the medical expenses, as related to the duration of the need for treatment, did not cause a strain on the family. However, the family felt that had the patient received treatment on a paying basis, the expenses might have been a financial hazard for them.

Ten of the fifteen families did experience changes. Five of these saw their insurance and other health benefits exhausted as a result of the cost of treatment and duration of the illness. Among these, four had to accept and solicit financial help from relatives, church, and/or friends. Four families had lost either the sole breadwinner or one of

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[1] Frances Upham, A Dynamic Approach To Illness (New York, 1953), p. 19.

their wage earners and were planning to seek welfare assistance. The breadwinner was lost in one family and the wife was forced to seek employment and other means to make up for the income lost. In five of the ten cases, the families had to accept a decrease in income through social security and/or public assistance because the patients were forced into employment retirement by the illness.

The researcher has shown that five of the fifteen families through the help of public facilities did not experience a financial strain because of the illness. Five families had to seek welfare assistance shortly after the onset of the illness because the loss of the patient meant the loss of support for the family. One family was able to use its own resources for a possibly temporary adjustment. This was made possible through a shift of roles. Four of the families were able to use their own resources temporarily, but the duration and expense of the illness was forcing them to seek financial assistance.

The study also revealed that four of the families found their greatest financial problem was paying for private medical care. When they were no longer able to pay for this care, they were sent to Cook County Hospital for treatment. As indicated before, with five of the families, the loss of the breadwinner seemed the most important factor. In the families where decreases in the income were due to receiving agency help, the changes in the family budget were complementary with the decrease in the income. In the instances where the family income was stopped by the loss of the breadwinner, it was impossible to measure expenditures.

None of the families reported having to purchase extra patient care equipment. The researcher feels that this may have been due to the fact

that the study did not include the areas of the body which might impose these problems. Except in the instances where the medical expenses of private care had exhausted family health benefits the sample group did not express that there were extra expenses for medical care. The fact that they were able to receive free care at Cook County Hospital or other agency help seemed to alleviate this problem.

Changes in Family Functioning

According to Koos, each family member has a pattern or patterns of behavior (roles) to perform so that the group may function. If, for some reason a member fails to carry his role the family can hardly carry on its tasks in the best fashion.[1] It has been indicated by many authors that for families illness usually means shifts in roles and relationships to meet the needs created by the vacancy caused by the illness. With the implications of a disease like cancer this could mean permanent losses of roles and/or changes and adjustments to new ones.

> "If the patient is the man and breadwinner, the standard of living, plans for the future, and entire tenor of life may have to be changed...If the patient is the mother and homemaker, all the effects of the temporary dislocation of the family life seen in acute illness are intensified and multiplied."[2]

Among the roles carried by the fifteen patients in relation to the immediate members of the family known to the researcher were mother, father, wife, husband, grandmother, sister, homemaker, breadwinner, and wage earner. The researcher found a variety of changes of roles as a

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1 Earl Lomon Koos, The Sociology of the Patient (New York, 1954), pp. 58-59.

2 Minna Field, Patients are People (New York, 1953), p. 160.

result of the patients' illness. In two instances, the wives who had never been employed before had to become wage earners. A few shifts were noted in who took the responsibility for management of affairs outside of the home, household duties, and care of the children. Although these problems appeared infrequently, it is worthy to note that they can exist where illness occurs.

As mentioned earlier, we sometimes must think of some cancer patients in terms of a permanent loss in the family relationship. Illness can cause loss of place in the family whether the patient is father, mother, or child; it frequently entails a permanent readjustment for each person in the home.[1] The following case illustrates something to be considered in terms of a permanent loss to the already fatherless children of one family.

> In the K case, the divorced mother of eight children was incapacitated by cancer of the ovaries with metastasis and was in her pre-terminal stage. The mother had the help of homemaker service and relatives with the managing of her home. However, when she dies these children will be without parents.

The above case extract was meant to point up the social impact an illness like cancer can have on families in terms of meaning the temporary or permanent loss of important role participants. Whether this loss be temporary or permanent, it can be affirmed that role vacancy calls for changes and adjustments. None of the families studied indicated a problem with having to give up or postpone roles outside of the home which include marriage, career, and/or education. According to the literature this could be a problem with illness. However, it was not represented

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[1] Upham, op. cit., p. 49.

in this sample.

Changes in Daily Routines

> "The presence of a sick person in the home affects the life of the family, altering both its major aspects and minutiae of everyday living."[1]

With illness, especially when the patient is being cared for at home, there may occur changes in the way the family's time is spent and the amount of time spent in carrying out daily chores and activities. Two interviewees stated that their work time was shortened by having to care for the patient. Seven complained that their sleep and rest hours were shorter due to the need for supervision and care of the patients. Over half of the families could note no change in this area.

Sometimes illness can interrupt the routine of families who do not live in the same household of the patient. This case extract may illustrate this problem.

> In the K case, it was recommended by the doctor that the patient have medical supervision for twenty-four hours daily. The patient's brother and sister-in-law rotate daily to provide this service. When the brother returns from work he goes to his sister's home to remain until relieved by his wife or another relative. The brother has three children of his own. These children must live with a maternal grandmother, because both parents help with the patient.

The case just cited should show that it is possible for families to be disorganized by cancer. Whether by choice or necessity, illness can cause people, temporarily, to neglect their own responsibilities.

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[1] Field, op. cit., p. 160.

Changes in Activity Participation

Family-centered activities seem to cement the family relationships and cause greater family unity. The sharing of activities tends to make for a more harmonious atmosphere in the home, security in relationship to the members, and for minimum conflict in interests. This seems to be the feeling of Charlotte Towle[1] and other authors on the subject of activities as related to family live.

Illness can disrupt family unity in that families sometimes are unable to participate together in activities as they had in the past. In eight of the cases studied, it was expressed that there had been some changes in the family's participation in religious, social, and/or recreational activities. Seven of these families indicated inability to attend church because of having to care for the patient. Two of the seven stated that they had been active participants in church organizations before the illness. In the remaining family, the wife indicated that she continued to attend church but that the husband or patient stayed at home.

All of the eight families indicated that because of the illness a number of social activities had to be given up. These included business and social clubs, and visiting and entertaining friends. The other seven felt that the illness had stopped them from being able to visit and socialize with friends.

Only one of the eight families felt that the illness interfered with

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[1]Charlotte Towle, Common Human Needs (New York, 1955), p. 86.

the family's participating in recreational activities outside the home. The members of this family had been active sports participants. Two of the eight families expressed that aside from the patient's being unable to participate with them, they had to give up these activities because of the expense. The remaining seven families in this sample adknowledged no change in their activity participation.

Changes in Living Arrangements

> "...Family members may find that the limitations imposed by the illness demand a rearrangement of their pattern of living which is difficult to achieve...Such changes in family living have to be made with the knowledge that it is not a temporary expedient but may have to be continued indefinitely."[1]

Illness may cause families to make changes in their living arrangements. It sometimes means that families have to move to other living quarters; they have to make arrangements for other family members to live with them, or they have to change the order of their living quarters to meet the needs provoked by the illness. It may also mean that some member of the family will have to leave the home for care elsewhere.

Nine of the fifteen families indicated problems in this area. Two of these had to move to new living quarters which were less expensive because the illness had made changes in the financial and economic situation which warranted this. Another family member stated that her family had a lease for their quarters which they felt they could not afford to keep nor could they afford to give it up.

Another two of the seven families indicated that they had to make

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[1]Field, op. cit., p. 175.

room in their homes to accommodate the patients whose illness necessitated that they not live alone. One of these two complained of having to give up their little daughter's bed room to make room for the patient; the little girl had to sleep in the room with her parents. Still another family in the sample told of having to make a place for the patient to sleep because of some of the effects of the illness were not conducive to his sleeping with anyone. In the remaining three of the nine families, the patients had been re-hospitalized which meant that one less member was now living in the family. The six other families of the sample indicated no problems in this area. Even though it was reported that some families moved to other living quarters as a result of the illness, it was not indicated that their moving made any difference in the distance from work, church, school, and/or social contacts.

The researcher found that cancer can cause varied social problems for families to which they will have to adjust. These problems may manifest themselves in terms of changes and losses of persons and/or things that may be considered essential to wholesome family functioning. The researcher devoted the following chapter to a consideration of some of the emotional problems associated with cancer as they may involve the families of cancer patients.

CHAPTER IV

EMOTIONAL IMPACT OF CANCER ON THE FAMILIES STUDIED

> "To the community at large, a diagnosis of cancer is tantamount of a death sentence. It is the big "unmentionable", not to be referred to at all if possible and when it cannot be avoided to be mentioned in a hushed voice a conspiratorial tone... The professional team caring for the patient reflects the same attitudes."[1]

Cancer seems to be a particularly dreaded disease because of the great deal of uncertainty about its cause and treatment and because frequently for patients it means mutilation and annihilation. It can also mean long convalescent periods with medical care and supervision which can be taxing to both the family and the patient.

Changes in the Attitudes of Patients

At some hospitals there is the tendency on the part of the physicians to generalize regarding the policy about revealing the diagnosis and prognosis to patients.

> "There have been sharply differing attitudes in the medical profession about whether to reveal diagnosis to a cancer patient... The philosophy opposing sharing diagnosis is the more entrenched and long standing one, whereas those who argue for greater candidness with patients represent more recent thinking."[2]

Some authors such as Upham and Goldstine have indicated that fears of patients are often multiplied when the physician does not tell them the diagnosis or discuss the illness freely. However, Jablon and Volk suggest

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1 Field, op., cit., p. 72.

2 Rosalind Jablon and Herbert Volk, "Revealing Diagnosis and Prognosis to Cancer Patients", Journal of Social Work, Vol. 5, No. 2 (April, 1960), p. 52.

certain guides which might be useful in differentiating whether to reveal a diagnosis of cancer to a patient. These guides are age of the patient and stage of the disease. Furthermore, they stated that these criteria are to be understood as guides, not substitutes, for differential diagnostic judgment with each patient. "The significant individual characteristics of each patient must always be considered."[1] Some findings with regard to patient's reactions seem to suggest that the application of the latter theory of Jablon and Volk needs more consideration.

Most of the patients involved in this study had not been told they had cancer. The less threatening word "tumor" was substituted for cancer.

Fear and anxiety.--George Crile suggests that people have been taught to fear cancer. He seems to feel that one of the most dangerous things about cancer is the fear of it. He states that it is no harder to live with and no worse to die of cancer than any other disease.[2]

In all fifteen of the cases the patients gave indication of apprehension and anxiety about their illness at some point during its duration. However, in some instances this was substituted by or changed to what seemed a passive acceptance attitude.

In two of the fifteen cases the interviewees reported that since the illness the patients had become anxious and continuously questioned their wives about their illness. Other changes noted in these patients' behavior were that they had become depressed and irritable. In other families in

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1 Jablon and Volk, op. cit., p. 57.

2 George Crile, Cancer and Common Sense (New York, 1955), p. vii.

the sample the same kinds of attitude changes were noted. However, the interviewees felt that along with the concern about the physical implications of the illness, the patients were also concerned about the incapacity and inability to function as before. In one of these two cases it was stated that the patient avoided talking about the illness.

"Any illness may provide conscious or unconscious fears and create resistance to seeking medical advice."[1] The following case extracts should show some indications for delay in seeking medical help as they were applicable to some of the patients involved in this study, and as they were reported by the family members:

> In case C, it was indicated that prior to the illness the patient would not seek medical attention and would jeer other family members who had frequent medical checkups. When the symptoms of cancer became very prevalent the patient begged family members to seek medical help for him.
>
> In case G, the interviewee reported that at the onset of the illness, the patient was reluctant to accept medical help because of fear of hospitalization and concern about the incapacitation of convalescence.
>
> In case L, the interviewee felt that the patient delayed seeking medical attention at the onset of the illness because of the fear of financial expense and hospitalization.
>
> In case N, the family members expressed that the threat of incapacitation and inability to function as before was the major factor in the patient's failure to seek medical help at the onset of the illness.

Most prevalent in the preceding case extracts were the fears associated with the illness. Each patient seemed to be concerned about what the illness would mean to him in terms of his life functioning.

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[1] Upham, op. cit., p. 161.

Attitudes of Resignation.-- For the purpose of this study the researcher defined the concept of attitude of resignation as an attitude which implies that the person feels that having cancer means inevitable death. The following case extracts will indicate this assumption.

> In the F case, the husband stated that the patient's attitude had changed for the better since the illness. He indicated that prior to the illness the patient was quite temperamental, but has become more calm. She admits that she suspects she has cancer and wishes her husband to find out from the doctor whether this is true. She states that she feels she is going to die anyway.
>
> In the I case, the patient was told by family members that she had cancer which the doctors felt had been treated. Patient seems more intent on doing everything right, and continuously states that if it is her time she is ready.
>
> In the J case, it was indicated that the patient knew her diagnosis and also had been successfully treated. The family member felt that shewas still a little anxious about her prognosis but continued to function as before.
>
> In the M case, the patient left the hospital against the advice of the doctors and with the understanding of his diagnosis. He states that he feels he is going to die.

It seems in these instances that the patients were able to accept their illness in terms of not letting it interfere with their functioning. However, in their reactions was the element of feelings of hopelessness.

Personality problems associated with attitudes toward the illness.--

> "There are often severe changes in the behavioral reactions of individuals which are associated with physical damage or stress. For example, when we suffer from a cold we are aware that our behavior may become more irritable. When we are tired or fatigued we may react differently. More profound behavioral reactions may result from physical disease processes, malfunctions, or injuries."[1]

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1 Max L. Hutt and Robert Gwyn Gibby, Patterns of Abnormal Behavior (Boston, 1957), p. 10.

Already mentioned have been some changes in the patient's attitudes as related to his illness. This section attempts to illustrate that illness may cause changes even in the more severe or abnormal personality. In two of the sample families, there was a history of the patient's being mentally disturbed before the illness. One of the patients had a history of a state hospital commitment for about fourteen years; her diagnosis was Melancholia. Her family reported that the illness seemed to have intensified an already prevalent disturbance. This was also true of the other case where the patient seemed to have changed from a hypersensitive person to one exhibiting paranoid behavior.

Attitudes of Family Members Toward the Illness

There are many frustration-provoking circumstances associated with an illness like cancer. In addition to adjusting to the social problems created by the illness, and to the changes in the behavior of patients, families have to come to grips with their own feelings. Family members realize the implications of an illness like cancer and have their own fears and anxieties concerning these. In many instances, as is the case with most of this sample group, the family is burdened with the responsibility of sharing with the doctor the patient's diagnosis and prognosis and keeping these matters from the knowledge of the patients. Jablon and Volk stated that in the medical profession, general agreement exists only about the need for sharing diagnosis with a responsible relative.[1]

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[1] Jablon and Volk, op. cit., p. 74.

The researcher found, either by coincidental circumstances or direct bearing, that there was a relationship between the families' knowledge of the diagnosis and prognosis and the type of response received from the family members. The family members who had not been told by the doctor what the diagnosis or prognosis was or who denied understanding the doctor's interpretation of the illness, showed less emotional upset than the others. Their concerns seemed to be about the inconveniences and hardships the patient's incapacitation had caused the family. This type of response was prevalent in four of the fifteen families studied. The variant factors in this group were with relation to their knowledge about the illness. One interviewee had not been told the patient's diagnosis because she was ill and it was felt that this knowledge would affect her health condition. Another family member had seen X-rays of the tumor but did not seem to understand the implications; she referred to the cancer as a "pilot". In still another of these four families, it was reported that the interviewee had not talked to the doctor about the patient's illness because he had never been able to contact him. However, his wife suspected that she had cancer and had encouraged him to seek confirmation or denial of this from the doctor. The husband felt he could accept and adjust to the patient's having cancer. In the remaining one of these four cases the wife denied being able to remember the patient's diagnosis. She stated that she felt the illness was something like an "ulcer". However, she understood the prognosis, but showed no overt concern about this.

In the other eleven cases in the sample group the responses to the

illness were anxiety and fear. In some instances the family members seemed to be responding to the diagnosis of cancer, and in others they seemed to be responding to the physical effects of the illness. In the cases where it was felt the cancer was cured or where the doctors felt the tumor was not malignant, there still seemed to be an element of anxiety. Because of previous information to the contrary there were some doubts as to the authenticity of the later prognosis.

A person's experience with and knowledge of particular kinds of situations can influence the way he will respond in similar situations. It seemed indicated that family members might have been responding to a diagnosis of cancer. This can be seen in the following excerpts from data collected for this study.

> In case A, the interviewee stated that she was upset about her husband's condition because no one liked to know there was cancer in the family.

> In case M, when asked how she felt about patient's illness she stated that she was afraid of cancer. She had watched the mutilative effect of the disease with her cousin and was just waiting and watching for the same thing to happen to her husband. This experience seemed quite upsetting for this wife. Under the pressures of her own anxieties and fears she cannot discuss any aspect of the illness with the patient.

The preceding case extracts point up what the researcher felt were two instances which indicated that the family member's response to the diagnosis of cancer was predisposed by his preconceived ideas and previous contact with the disease.

As mentioned earlier, the researcher felt that in some of the families studied, the response was in terms of the present physical effect the illness had on the patient. In one case, the interviewee described the

patient's illness by stating that there were malignant tumors running around in the patient causing him to experience the changes in his appearance and health. She described her husband as being nothing but skin and bones which cannot do anything.

A response that seemed to indicate the families' feelings about cancer in spite of having received a favorable prognosis from the doctor can be illustrated in the following case extract.

> In the I case, the family had been told that the patient's tumor was not malignant. They expressed feelings that the doctor may have been trying to protect them from the truth.

This type of response was seen in two other of the cases in the sample group. The family seemed uncertain or skeptical about accepting the doctor's prognosis. In still another instance involved in this sample the family member denied the fatal prognosis that the doctor gave the patient.

Some other elements of fear and concern which were expressed during this study were the fear of contagion and the fear of heredity. In one case the family had stopped having visitors and had assigned special equipment to the patient to avoid "catching the disease". In another family where persons of two preceding generations of the interviewee had cancer, some fear and anxiety was expressed concerning the possibility of inheriting the disease.

Anxiety and fear seemed the most prevalent emotional reactions of both the patients and their families in this study. However, there were differences in the way these were manifested. It was indicated that patients can be frustrated by the implications of the illness even if

they are told the diagnosis. Families must carry the burden of knowledge of the illness, and must face the interrogations of the patients with various mechanisms to conceal the truth.

CHAPTER V

SUMMARY AND CONCLUSIONS

The social and emotional implications of an illness like cancer are profound and extensive. There was indication of a need for continued exploration concerning the problems that are created by this illness. The researcher recognized that information gotten from a study such as this could possibly be useful, if only as a guide for further study, to professions with interests in this subject. The present trend in both the medical and social work profession is to bring the environment, especially the family, into treatment. The researcher felt that a study such as this would be in keeping with this trend and possibly yield some information to help substantiate the need for this service. The researcher undertook this study to find out the impact of cancer on the families of fifteen cancer patients known to the general tumor service at Cook County Hospital, Chicago, Illinois.

It was the researcher's objective to discover and report some of the social and emotional problems created by and associated with cancer as identified by the family members who lived with or in proximity of the fifteen patients. Perhaps this study could point up some of the problems which are unique to an illness like cancer.

The data were collected for this study during the months of January and February, 1961. The researcher with the aid of a schedule interviewed members of the families of the fifteen patients who were selected for this study.

The limited amount of time which could be devoted to the study and the inexperience of the researcher were factors which contributed to the

inability to do a more intensive study or one on a larger scale with the use of more effective methods. This study pointed up many varied and complex situations. This limited the chance of this study's confirming probabilities. However, the study may be useful in showing possibilities.

The data were reported in terms of social problems and emotional problems of the families studied. These matters are handled in chapters III and IV respectively. The problems dealt with in chapter III were social ones involving changes which occurred in the pattern of living of the family as a result of the illness. These problems were described as changes in the financial and economic situation, changes in family functioning, changes in daily routines, changes in activity participation, and changes in living arrangements.

The study substantiated the possibility that illnesses, such as cancer, can cause problems and changes in the above named areas. In ten of the fifteen families studied, their financial status was lowered; in five of these, their income was exhausted by medical expenses of the illnesses; four families lost a breadwinner or wage earner; five families were forced to seek public assistance or other means to make up for their budget deficits. The five families which did not experience a financial strain were receiving public assistance before the illness.

For most of these fifteen families, the illness caused shifts in roles to fill the vacancy left by the patient's incapacitation. Cancer sometimes means that the new arrangements may be permanent as well as temporary. Sometimes, as was indicated by seven of the families, having to care for the patient interrupts the family's daily routines in terms of chores and activities. These things had to be delayed in some instances and/or done

more frequently in others.

In eight of the fifteen families, the illness created changes in the number of activities participated in since the patient's illness. Aside from not having the patient participation in the activities with them, two families expressed an inability to enjoy themselves outside the home in club activities because the expense was too much since the illness.

Nine of the fifteen families indicated a problem involving changes in living arrangements. The problems associated with changes in the living arrangements concerned having to care for the patient at home which called for some adjustments; this involved six families. In two families, older family members had to move in with younger ones. Three patients had to be readmitted to the hospital. Two families had to move to new living quarters because the changes in their financial situation as a result of the illness warranted this. One family experienced a situation where even though they could no longer afford their living quarters, they were held there by a lease.

As described in chapter IV, the emotional reactions most prevalent were fear and anxiety. The researcher reported the reactions and/or attitudes of the patients in terms of what changes had been noted since the illness. This was in order to discover what changes in the patient's attitudes the family members had to adjust to when faced with a diagnosis of cancer.

Most significant were the persistent requests of one or two of the patients concerning their diagnosis. On the other hand, there was indication of the struggle of the family members to handle their own

feelings and to protect, upon the doctor's orders, the patients from learning about their diagnosis and prognosis.

In eight of the families, it was indicated that uncertainty about the illness causes a great deal of anxiety. Another thing to be considered is that with four families, the fear of cancer caused the patients to deny help and/or in other ways to give up to a fatalistic attitude. In two families, where the patients had behavior disorders prior to being diagnosed, the family members felt the illness intensified these mental problems.

In eleven of the families, the family members responded to the illness with anxiety and fear. These attitudes manifested themselves in concern about the diagnosis, prognosis and the symptoms and effects. In two of the families, there was the fear of contagion or possibility of inheriting the disease.

It would be hard to draw conclusions which would be substantial, from such a limited study. However, it could be said that the findings indicate a possibility that some of the same kinds of problems may occur with other families with cancer patients.

Generally speaking, cancer and its accompanying problems can disrupt the normal functioning of the family. It is difficult to say whether persons respond to the word "cancer" or the implications of the illness as manifested by the symptoms and effects. This matter should be considered in the light of revealing diagnosis and prognosis, to the patients and families. Another thing pointed out in this study which might be suggested for further exploration, is the matter of considering that families are people with regard to giving them the sole burden of

knowledge and acceptance of the patient's condition with the responsibility of keeping this from the patient. If this is to be their lot, perhaps ways could be developed in terms of helping them to handle their fears and anxieties about this. There seems to be a need for a clearer and more meaningful interpretation of the patient's illness to the family which might help to alleviate some of the emotional impact associated with this illness.

It seems that families, too, need help with their feelings as well as with the concrete problems centered around cancer. Perhaps this study can serve to focus a future inquiry around this subject.

APPENDIX

SCHEDULE

I. Was the pt. the (1) Mother_____ (2) Father_____

(3) Wife_____ (4) Husband_____ (5) Daughter_____

(6) Son_____ (7) Sister_____ (8) Brother_____

(9) Homemaker_____ (10) Sole Breadwinner_____

(11) One of the Wage Earners_____ (12) Others_____

II. Since the Patient's illness have you had to help with

A. Care of the children? Yes_____ No_____

1. If so, who has been giving this help?

Relative outside of home_____

Homemaker Service_____

Neighbors_____

Friends_____

Salvation Army_____

Cook County Welfare_____

Others_____

B. Household duties? Yes_____ No_____

1. If so, who has been giving this help?

Relatives outside the home_____

Homemaker Service_____

Neighbors_____

Friends_____

Salvation Army_____

Others_____

C. Management of affairs outside the home (paying bills, shopping, marketing, etc.)

If so, who is giving this help?

Relatives outside the home _____

Neighbors _____

Friends _____

Others _____

D. Financial Support Yes _____ No _____ Partially _____

Totally _____

1. If so, who has been giving this help?

Relatives outside the home _____

Neighbors _____

Friends _____

Public Assistance _____

Social Security _____

Others _____

III. Has anyone in the family had to

A. Start working Yes _____ No _____

B. Stop working Yes _____ No _____

C. Work shorter hours Yes _____ No _____

D. Change Jobs Yes _____ No _____

E. Others _____

IV. Have there been any changes in how the family budget is spent for

Food _____ More _____ Less _____

Rent _____ More _____ Less _____

Medication _____ More _____ Less _____

Clothing _____ More _____ Less _____

Amusements _____ More _____ Less _____

Gifts _____ More _____ Less _____

Others _____ More _____ Less _____

V. Have you had to purchase extra patient care equipment?

A. Special Cooking Utensils Yes _____ No _____

B. Dressings Yes _____ No _____

C. Medication Yes _____ No _____

D. Bed Linen Yes _____ No _____

E. Tools for Administering Medicine Yes ____ No _____

F. Irrigating Equipment Yes _____ No _____

G. Hospital Bed Yes _____ No _____

H. Special Bed Tray Yes _____ No _____

I. Other Equipment Yes _____ No _____

VI. Does the family have extra expenses for

A. Medication Yes _____ No _____

B. Diet Yes _____ No _____

C. Treatment Yes _____ No _____

D. Doctor's Fees Yes _____ No _____

E. Other Expenses Yes _____ No _____

VII. Has the family had to make changes in living quarters?

A. Get additional furniture Yes_____ No_____

B. Change sleeping arrangements Yes_____ No_____

C. Change the order of the rooms Yes_____ No_____

D. Other changes_____

VIII. Has the family had to move to new living quarters?

If so, for what reasons?

A. Inadequate space_____

_____

B. Inadequate facilities_____

_____

C. Less expense_____

_____

D. Other reasons_____

IX. Has the moving to new quarters made any difference in the distance from

A. Work Yes_____ No_____ Farther_____ Closer_____?

B. Church Yes_____ No_____ Farther_____ Closer_____?

C. School Yes_____ No_____ Farther_____ Closer_____?

D. Friends Yes_____ No_____ Farther_____ Closer_____?

E. Entertainment Yes_____ No_____ Farther_____ Closer_____?

F. Other Social Contacts_____

_____?

X. Since patient's illness has anyone had to give up_____or postpone___

A. Education_____

_____

_____?

B. Marriage_____

_____

_____?

C. Career_____

_____

_____?

D. Other Items_____

_____

_____?

XI. Has caring for patient caused any changes in the family's participation in

A. Religious Activities_____

_____

_____?

B. Social Activities_____

_____

_____?

C. Recreational Activities_____

_____

_____?

D. Educational Activities_____

_____

_____?

E. Other Activities_____

_____

_____?

XII. Have there been any changes in the customary daily routines as to how much time is spent or how often the following have to be done

A. Cleaning_____

B. Laundering_____

C. Serving Meals_____

D. Cooking_____

E. Studying_____

F. Sleeping_____

G. Other Chores_____

_____?

XIII. Have you noticed any changes in patient's behavior since the illness?

Yes_____ No_____

A. If so, what_____

_____

_____

XIV. What do you know about patient's illness?

XV. How did you feel when you first learned of patient's illness?

XVI. How do you feel about it now?

A. If the feeling has changed, why do you feel differently about it now?

FACE SHEET DATA

Identification Number _____

Number in Family _____

Relationships _____

Ages _____

Religious Status _____

Source of Income _____

Date of the Interview _____

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